Utah Environmental Public Health Tracking Network

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Issue 10

EPHTN Roles: How do You Fit and Benefit?

The Environmental Public Health Tracking Network (EPHTN) is affected by a variety of people who play different roles in the network's implementation and uses. From data providers down to the general public who will view data from their own home, the workings of the network are complex and rely on participants with varied duties to ultimately improve public health. This newsletter will examine the roles we all play to make the EPHTN a success, and how it can benefit each of us.

Data Stewards
The EPHTN begins with data. This valuable information comes from data stewards. In the EPHTN, a data steward is a person or agency that collects and maintains primary environmental or health data. The data steward may also generate secondary data from or about the primary data, such as deriving age from birth date.

Data stewards for the Utah EPHTN include partners like the Utah Division of Water Quality and the Utah Injury Registry. A state statute or a reporting rule authorizes data stewards to collect data. In addition to authorizing collection of data for a registry, the law or rule may specify

data use, maintenance and protection requirements, constraints and other data steward responsibilities for the data maintained in the registry. The EPHTN does not collect its own data, but relies on data stewards to collect and share their valuable information. Simply put, the EPHTN would not exist without help from data stewards.

Sharing data with the EPHTN comes with some risks for data providers. These risks come with making potentially sensitive medical records available to the public through the

Data stewards keep primary environmental and health data

network. Although the data are turned over to the EPHTN, the data steward is ultimately responsible for the appropriate use and safeguarding of those data. Recent changes by national legislation such as HIPPA increase safeguards for patient

EPHTN Roles *(cont.)*

information privacy and increase the liability of data owners and data stewards regarding data collected on individuals.

However, the EPHTN takes every precaution available to protect the data from misuse. The EPHTN maintains a third-party access agreement process that must be completed by anyone who wishes to gain access to entire data sets. The agreement requires the approval of a series of forms including an application, research proposal, scientific review board approval and research agreements. The EPHTN is also concerned with the safety of the electronic network, which will be built

The network is designed to be secure

to meet Department of Homeland Security information security standards.

Data stewards voluntarily provide data to the EPHTN. Although the EPHTN cannot pay providers to share their data, there are benefits to contributing to the network. The network can help increase the amount of people exposed to an organization's data, which can increase the organization's scope and scale. The network will help contributing public health organizations by allowing them to use their data in conjunction with environmental or health information from a variety of other sources. Also, the EPHTN can provide helpful services to data stewards such as geocoding and data standardization.

There are costs and benefits to data stewards who share their data with the EPHTN. However, the public health benefits of the EPHTN are worth the data stewards' efforts.

EPHT Project Updates

- **CDC has released a "coffee table book" that highlights the successes and challenges experienced by the national EPHT Program. For a copy of the book, please contact Adam Owens at aowens@utah.gov.**

- **The Technical Advisory Group (TAG) meeting was held on December 13, 2006. TAG members reviewed both the TAG Operational Plan and the 3rd Party Application Policy and Process. The EPHTN thanks all of the TAG participants who contributed to the meeting.**

- **The Utah EPHTN is completing a marketing packet that will serve to inform current and potential partners about the need for a tracking network.**

- **CDC's "Tracking 101" is almost ready. The complete training program will be available to EPHTN staff on January 31. The Tracking 101 course will be presented to partners and local health departments in February or March.**

Data Custodians, Managers and Users

Although shared data still remain the property of data stewards, the data are turned over to data managers and data custodians who see that they eventually reach appropriate users.
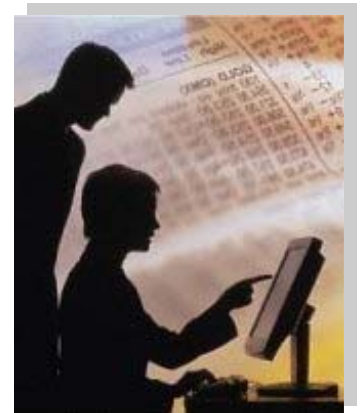
Data Custodian
The data custodian is a role assigned to agencies that acquire, use and store registry data obtained from a data steward. Data custodians are the caretakers of borrowed environmental and health data. The data custodian acts on behalf of the steward to ensure that the data from the registry are stored, maintained, distributed and used appropriately.

The Utah EPHTN is a data custodian for data maintained in the EPHTN warehouse. The CDC is a custodian for data maintained on the national EPHTN. The data custodian's responsibilities are outlined in a data sharing agreement with each provider.

> **Data custodians are the caretakers of borrowed environmental and health data.**

The Utah EPHTN primarily maintains a warehouse with data from many partners. The Utah EPHTN processes shared data so they can be associated with other data in the warehouse by location or time. While the Utah EPHTN may also use the data in the warehouse to conduct public health investigations, the primary objective is to make the information available to other public health investigators and to the general public.

Public health investigators who use data from the EPHTN data warehouse assume the role of a data custodian as well. To ensure investigators correctly fulfill this role, the Utah EPHTN requires them to complete agreements assuring the maintenance, security and use of the data are appropriate and in compliance with the requirements of the data steward. To do this, the Utah EPHTN established a Scientific Review Board comprised of representatives from the data steward agencies to review and approve use plans for their data.

Custodians maintain the data

Data Managers
Within the data steward and data custodian agencies, data managers are the technicians who maintain and protect their organization's data. The manager has access to the raw-level data within the data management system, and has the ability to manipulate them. The data manager prepares data for use by a data user.

Data Users
Data users are the professionals who will use the data to conduct public health investigations. Data users conduct analyses to investigate public health concerns, test hypotheses, measure the results of intervention actions or assess other public health functions. In some cases, the data user may also have data management roles.

Regardless of which of these three roles a particular person may play in the building and implementation of the network, he or she will need to be trained and required to protect sensitive data. Every role will be important in building and maintaining the EPHTN.

The Important Role of the Public in the EPHTN

In addition to the professionals who collect and maintain the EPHTN data, the public will also play an important role in the network.

The ultimate goal of the EPHTN is to improve health by informing communities about their environmental risk factors and health. In order to reach this goal, the EPHTN must reach the public. As the public becomes more informed about public health and the environment, public health will improve.

The system in place for allowing appropriate information to reach the public is the Indicator-Based Information System for Public Health (IBIS-PH). IBIS-PH is a portal, or Website where public users can access some of the network's data. This level of public access will lead to healthy, informed communities as residents, developers and others become better informed about important decisions regarding environment and health.

The EPHTN will improve public health agencies' abilities to inform communities of environmental health hazards. The EPHTN will be a comprehensive surveillance network and an effective tool for identifying and describing existing and emerging environmental health hazards and illnesses.

The network will also allow researchers and agencies to conduct inexpensive and quick research. The research will help link human exposure to environmental hazards and health status. The network will also allow researchers to consider multiple health outcomes of an exposure to an environmental hazard.

These improvements in our ability to track environment and health will help slow the increasing prevalence of chronic diseases. The network will also reduce the billions of dollars in costs related to environmental illness. The data the network will make available will also help protect Utah's large population of children, who are disproportionately affected by environmental heath hazards.

Although much of the public may not directly use the EPHTN, its effects are far reaching. The network will influence decision-making and practices on local, state and national levels that will benefit public health.

> **This level of public access will lead to healthy, informed communities...**

New Utah EPHTN Logo

The Utah EPHTN has adopted a new logo. We will now be using a button-style logo that represents hazards, environment, human exposure and health. The logo features the phrase: "Bringing heath and environment together." The new logo will now appear on EPHTN publications and materials to represent the Utah EPHTN.

The new Utah EPHTN logo

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EPHTN Benefits Public Health

With the help of important players such as the public, researchers, and data stewards, environmental health tracking is benefiting public health all over the United States. For example:

- Tracking in Utah has allowed once cumbersome and timely public health investigations to be carried out with a fraction of the time and cost.

- California's tracking network has made easily understood agricultural pesticide use data available to the public online.

- In New Hampshire, the state environmental tracking network provided access to 14 years of health and environmental data to investigate a suspected cancer cluster.

Future Activities & Important Dates

- The CDC course "Tracking 101" will be presented to partners and local health departments in February and March.

If you have any events you would like posted in the next (spring) newsletter, please contact Adam Owens at aowens@utah.gov.

WE'RE ON THE WEB WWW.HEALTH.UTAH.GOV/EPHTP

Utah Environmental Health Tracking Network

Mission: To develop a state-wide, standards-based, Web-enabled tracking network information system in Utah to enable information and knowledge dissemination and improve public health in the realm of chronic diseases related to environmental factors.

Contact Adam at aowens@utah.gov if you have an article or news you would like in the upcoming Utah EPHTN newsletter